

Witness Name: AMANDA LOUISE WEAVING

Statement No: WITN1595001

Exhibits: WITN1595002-WITN1595007

Dated: February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF AMANDA LOUISE WEAVING

I, AMANDA LOUISE WEAVING, will say as follows:-

Section 1. Introduction

1. My name is Amanda Louise Weaving. I was born on GRO-C 1967 and I live at GRO-C GRO-C Kent, GRO-C I have a partner who I do not live with and two children. I am a qualified Occupational Therapist.

COLIN JAMES SCOTT

2. My dad was Colin James Scott. He was born on GRO-C 1937. He died 1st December 1987, aged 50 after contracting HIV from Factor VIII (FVIII).
3. My dad married my mum, Valeria Ann Smith, in 1964. My mum had a part time job, but couldn't work full time as my Dad was always in and out of hospital. Despite his illness, we still financially relied on my Dad who was an accountant for the University of Kent, where he worked from 1965 until he died. When I was younger I lived at home with my parents and my brother. My mum died in 2011.
4. My Dad was a member of the Haemophilia Society. He set up the Kent branch. When young children were diagnosed with Haemophilia my Dad would help talk to the families with Dr Winters.

Section 2. How Affected

5. My dad had severe haemophilia A.
6. I believe my Dad started using FVIII in the late 70's, when I was nine or ten. I remember this as his use of FVIII meant we could go on holiday for the first time. We went to Switzerland by car, because my dad could not travel on planes.
7. My dad was under the care of St Thomas' Hospital where he had operations under Dr Jeff Savage, and when Dr Savage retired, he was under Mark Winters. He was also under the care of the Kent and Canterbury Hospital and Queen Elizabeth the Queen Mother Hospital, Margate.
8. I believe my Dad received infected blood products between approximately 1977 and 1987. I exhibit at WITN1595002 my Dad's Haemophilia database records which details treatment he had. I also enclose extracts from the limited medical records I have for my Dad which give further detail of the treatment he received.
9. My Dad did not tell me if he had received any information or advice about the risk of being exposed to infection from FVIII. However, I do strongly feel that if my Dad had been aware of any risks associated with the use of FVIII, he would have objected to being treated with it, as it would have added another layer of risk to his health. My mum had already taken the chance of having a family with a Haemophiliac, and so my Dad would not have accepted treatment which posed further risks to his health.
10. My Dad was infected with HIV and Hepatitis C as a result of being given contaminated blood products.
11. I exhibit at WITN1595003 a medical report which appears in my Dad's medical records which appears to be from Mark Winter to the Medical Defence Union. I also exhibit at WITN1595003 the Medical Defence Union's letter dated 20.7.89 which was in my Dad's medical records which appears to acknowledge Mark Winter's report.
12. I remember graphic and frightening adverts on the television about AIDS in the 1980's. When I was seventeen or eighteen and one such advert came on the TV and I recall my

Dad calling us all together and saying 'I'm afraid I have that as well, so it means I'm not going to be here for long'. He went on to explain that they were testing him for HIV and they may need to test the rest of us. I believe GRO-C I were tested.

13. I am not sure exactly how my dad found out he had HIV but he was ill at the time of the adverts. He had a cancer scare and the doctors couldn't work out what was wrong with him. I believe they then realised he had HIV. I imagine my Dad would have had an appointment with Mark Winters and he would have told my Dad about his diagnosis.

14. I do not think my dad had enough information about his infection. It all happened very quickly. I think people should be as informed as they can be. The National Health Service said they did not know anything about the infections, but I believe they knew a lot more than they maintained. At the time we thought HIV was a new disease and no one really understood what it was, but we did know that at that time there was no cure and the death rate was high.

15. Once we found out about my Dad's HIV infection, we were certainly all very concerned about how contagious it was and that my Mum was also going to get infected.

16. My Dad found out about his Hepatitis C diagnosis after he knew about the HIV. I imagine he would have been told about this by Dr Winter again, but I'm not sure. He told us all about this again. When my Dad was dying he wanted to know if it was due to his HIV, which had progressed to AIDS, or his Hepatitis C.

17. My Dad (and the doctors I believe) were more concerned about his HIV, so I do not believe he was given adequate information about his Hepatitis C infection.

Section 3. Other Infections.

18. I don't know if my Dad contracted any other infections other than HIV and Hepatitis C. He may have been infected with vCJD but I'm not sure. His HIV was too advanced for the doctors to care about anything else.

Section 4. Consent.

19. I believe my Dad was probably tested without his knowledge. There are things in his medical notes which I don't understand despite my own medical background. For example, I saw reference to research in his notes. I'm sure my Dad would have told us if he had consented to being involved in research.

Section 5. Impact

20. Due to being infected with HIV, my Dad stopped having physical contact with any of the family in case he passed on his infection. This was especially hard when my daughter was born, as he would have wanted to cuddle her, but he felt he couldn't. It was very frightening and heart wrenching.

21. Being diagnosed with HIV destroyed my Dad's hopes for the future. He became very depressed. It really changed his personality. However, my Dad always had a smile on his face even when things were really awful. He tried to stay positive but it sucked the life out of him. Before he was infected, he thought he would have a full life span and he was looking forward to retiring but suddenly that was all taken away from him.

22. He would never have consented to treatment with risks if he knew that his future could have been taken away from him.

23. I don't really know about the severity of my Dad's physical symptoms from HIV/Hepatitis C. I am aware that he got diarrhoea a lot. He also didn't do as much driving as he used to because he got tired. I don't know if that was due to his infections or his depression, but he physically appeared unwell.

24. GRO-A, one of my Dad's friends died in 1986 as a result of receiving infected blood products. He went blind and had skin boils. It was horrendous. Dad came home and said he didn't want that to happen to him.

25. My Dad's HIV infection led onto AIDS and finally his death. I exhibit at WITN1595004 a letter to the Coroner in Broadstairs from Mark Winter which states that he was satisfied that the cause of my Dad's death was a) Non-Hodgkin's Lymphoma (secondary to infection by the AIDS virus) and b) Haemophilia.

26. At the beginning of 1987 we went on holiday to Switzerland in April or May. I think my Dad knew he didn't have long left at that point and he had a bucket list of things he wanted to do. He tried to hide how ill he felt from the family. He tried to soldier on. He cried, which I had not seen before.
27. Dad took ill on the second week of the holiday and we had to return home. I think this was the first time I knew that his HIV infection had turned to AIDS. I exhibit at WITN1595005 a letter from Mark Winter to Dr Savidge at St Thomas Hospital around that time detailing my Dad's health and treatment.
28. My Dad died about ten weeks after we returned from holiday.
29. When my Dad was dying in hospital he was in his own room. The nurses would come in with protective suits on. He wore rubber gloves to hold my Mum's hand. In your dying days to have no human contact must be awful. It ripped the family to pieces.
30. I exhibit at WITN1595006 a letter from Mark Winter to Dr Richards, Consultant Medical Oncologist at St Thomas' Hospital detailing my Dad's condition towards the end of his life.
31. My father received AZT treatment for his HIV infection and pain relief.
32. I do not recall him having any difficulty receiving treatment.
33. I do not know what my dad's options were but I believe Mark Winters would have given him the best treatment he could.
34. I do not recall any physical effects from my Dad having AZT treatment, but I recall that he became very tearful and depressed. Around the time of his treatment, my Dad started isolating himself from people. He had previously been very sociable. He was a great Dad and had a lot of friends.
35. In terms of the impact of my Dad's infected status on his other treatment, at one point he was due to have an operation because his hip or knee needed to be replaced but the doctors decided they could not do it because of his HIV status. They didn't want to operate on someone who had HIV, as they didn't know how to handle him. My Dad's operation was therefore cancelled, which left him in a lot of pain.

36. The impact of the infections on my Dad was that he really stopped being part of the family, as he was so concerned he would pass his infections onto us. He stopped seeing his friends and going to Church. He kept people at a distance, which was not the kind of man he was before he had his infections.
37. After my Dad died, I moved away as I couldn't cope with what had happened. Subsequently, I have had to see my children grow up without a grandad, who would have done so much with them, but they had that taken away from them.
38. The stigma was also awful. My husband was in the army and we were told they were going to ask him to leave because of what happened to my dad. Fortunately, this did not happen but the fact it was even considered was appalling.
39. The stigma caused my brother to lose his job. He was a chef and I was told there was something in the newspaper about my dad. I was not in the country at the time, so I am not sure of the full details of the story the paper printed. As a family we did not talk about what happened to my Dad until a few years ago.
40. My mum died never having told anyone about my dad's infections other than really close family. She could not talk about her husband's death without bursting into tears. I am the same.
41. My Dad's infections and death led to my mum becoming isolated. She lost contact with the majority of her friends. People wanted to know what had happened to my Dad, but she couldn't talk about it. We told people he had cancer if they asked. The only friends my mum really had were her church friends, who were a comfort to her. I think they were sensible enough not to ask questions. Even now, if you meet somebody and tell them that your husband died of AIDS it's a massive thing. Would a new partner want to take on someone whose husband had died of AIDS?
42. As a family we didn't cope. GRO-C
43. My Dad died whilst my grandmother was still alive. She died around 10 years after him.
44. My father had some advice from a colleague and applied for medical retirement a couple of weeks before he died. If he hadn't have done this, I don't know how my mum would have

coped financially when he died as this provided her with a pension. I exhibit at WITN1595007 a letter from Mark Winter to the Pensions Officer at the University of Kent dated 25.11.1987.

45. My mum was 45 when he died and they should have had another 20 years of working life ahead of them. She went from having a husband who had a reasonable income to a retirement income. Financially it crippled her. She had to take student lodgers in to help pay the bills.

46. My Dad had not been able to get life insurance due to his infections, so if it had not been for my Dad's pension and the lodgers my Mum would have lost her home.

47. The University of Kent was very supportive of my Dad and were understanding about the amount of time he had off work.

48. I went to university in my late 30's and my mum could not help me as much as she would have liked to financially.

49. My mum never returned to work after my Dad died. She had not worked for so many years and had lost all of her confidence and the will to meet new people.

Section 6. Treatment/Care/Support

50. I am not sure if my Dad faced any difficulties obtaining support in relation to his infections.

51. I went to my GP and organised my own counselling. I got depressed a few years ago and my GP referred me to a counsellor. I was diagnosed with a general anxiety disorder and Post Traumatic Stress Disorder. I was also prescribed medication, but I stopped taking it as I didn't find it helpful.

52. I have found it helpful to be part of the Group Litigation and the Tainted Blood Group, as I feel as if we are finally getting some support. We felt extremely isolated before and felt as if we had no-one to talk to about what we had been through, but we now feel as if it is starting to be addressed.

53. My dad was also not offered counselling that I am aware of.

Section 7. Financial Assistance

54. My dad did not know financial assistance was available. He would have taken advantage of it if he had known about it.

55. I believe my Mum received an interim payment. I think she received £25,000 in 1998, but I am not sure where this came from.

56. In 2011 there was a class action against an American company which the Skipton fund managed. I received a compensation award of around £35,000.

Section 8. Other Issues

57. I am really glad the Tainted Blood campaign formed. We were all so fractured before the internet. We had no support. The government has done nothing to support or help us.

58. I recall once being in a meeting with Mark Winters and my Dad. Mark Winters said he was told to carry on using the FVIII in stock. He told us that he refused to do so, threw it away and ordered heat treated treatment, which was against NHS guidelines at the time. This was around the same time as when my Dad was diagnosed with HIV. I remember Mark Winters got into a lot of trouble for this and there was concern that he might lose his job.

59. I do not wish to be anonymous, but I wish to have my address redacted. I feel that I have kept quiet for long enough.

ROBERT KENNETH SCOTT

Section 1. Introduction

60. My uncle was Robert Kenneth Scott. He was born on the GRO-C 1946 or 1947 (I believe). He lived in Southborough, Tunbridge Wells with my grandmother when she was alive (she died in the late 1990's). Robert was unmarried. He was an administrator. He died in around 2001 as a result of Hepatitis C.

Section 2. How Affected

61. Robert had severe Haemophilia A.

62. Robert received FVIII treatment.

63. Robert received care at Kings College Hospital, London or St Thomas's Hospital. He used to go to Maidstone or Pembury Hospital depending on the treatment needed.

64. Robert was given infected blood products at the end of the 1970's/the start of the 1980's.

65. I do not know if he was given any advice about the risks associated with receiving blood products.

66. Robert was infected with HIV and Hepatitis C as a result of being given contaminated blood. I don't know if he ever had Hepatitis B.

67. I do not know how Robert found out about his infections. I would imagine he would have been tested when my dad found out. The two were very close and shared information.

68. I don't know what my Uncle Robert was told about his infections, but he would still give people cuddles. I used to wonder why he could do that but my Dad couldn't, so I assume he was given very little information.

Section 3. Other Infections.

69. I do not know if Robert contracted any other infections.

Section 4. Consent.

70. I do not know if he was treated or tested without his knowledge or consent or for the purposes of research.

Section 5. Impact

71. Robert never had many friends. He lived at home with my grandmother so I didn't notice the impact. In the later period of his life, Robert became depressed, which I don't think he was before.

72. When she was alive, my grandmother helped care for Robert. However, she died in the late 1990's and Robert had a period of around 4 to 5 years when he lived on his own and when he really struggled. He became more of a hermit, especially when my grandmother died. He did not see much of the family. He did not want to drive far because he was in pain.

73. Robert stopped spending money on haircuts and clothes and started to save every penny he had. I think he thought because he had no wife and he knew his health was going to decline he would need support and to be ready for the future. This meant he also didn't eat as well as he should have. It was a terrible way for someone to live. It completely isolated him. The haemophilia made it hard enough, but the infections made him isolate himself even more.

74. Robert's health declined and he struggled. He regularly went into private respite centres to receive medical treatment. He would come out feeling much better.

75. I do not know if he had further medical complications. He had bad skin that was treated once. His face swelled and he got boils. He went to a retreat and when he came back he was better.

76. Robert died from Hepatitis C in around 2001.

77. I do not know if he received any treatment.

78. I do not know if he had any difficulty accessing treatment, but knowing him as I did, he would have fought for whatever he needed.

79. Robert's death was a huge loss to the family. It was another person you could not talk about. We were not a big family anyway, so to lose another member was heart breaking.

80. The children miss their uncle. They did not have a grandfather or a Dad around, so having a great uncle was the only male role model they had in their lives. Robert's death was a massive loss to them.

81. Robert would never have spoken to anyone about his infections. He had no one to talk to, not even my Grandmother, as he didn't want to worry her by telling her about his infections. He didn't think she would cope. He was very private and anxious about everything. I don't know how he coped. My dad died in 1987 so there was a long period of time when he had nobody. He may have spoken to my mum but she was struggling herself.

82. My Grandmother never spoke about Roberts' infections. I assume she guessed he had been infected as she read the newspapers and had seen the adverts. The secrecy was hard. It was very hard not to be able to talk about my Dad or my Uncle because of the stigma associated with their infections. The family have not talked about it over the years.

83. Robert had to retire when he was in his mid 50's due to his health.

Section 6. Treatment/Care/Support

84. I do not know if Robert had any difficulty obtaining treatment, but I imagine he would have been proactive in trying to obtain what he needed. When my grandmother died and he needed support around the house, he thought he could not have anybody in because he was contagious.

85. If he needed help with a bleed or getting dressed he had no support. I was not in the country and my mum was an hours drive away. I do not know how he made himself a hot meal. We now know that you cannot catch HIV from sharing cutlery, but in the 1980's and 1990's there wasn't that awareness.

86. I do not know if he was offered any counselling due to his infections.

Section 7. Financial Assistance

87. We had a payment for Robert when we got the payment for my dad. I got a quarter of the pay-out as I was one of Robert's four beneficiaries, who were four cousins. I believe the payment was £25,000 which was shared between the four of us.

88. I do not know if Robert received any other financial support.

Anonymity, disclosure and redaction

89. I would be prepared to give oral evidence to the Inquiry. I do not wish to be anonymous.

Statement of Truth

I believe that the facts stated in this witness statement are true.

Signed.....

GRO-C

Dated...20-2-19.....